

OpenSAFELY Oversight Board meeting notes
30-09-21

Date & Time	30/09/2021 10:00 - 12:00
Attendees	<ul style="list-style-type: none"> ● Prof. Nigel Shadbolt (Chair) [NS] ● Dr. Ben Goldacre (OpenSAFELY PI) [BG] ● Seb Bacon (OpenSAFELY CTO) [SB] ● Becky Lumbard (OpenSAFELY Senior Project Manager) [BL] ● Amir Mehrkar (OpenSAFELY Head of IG and external relationships) [AM] ● Mark Coley (GP, BMA) ● Kevin Minier (Expert patient representative) ● Jeni Tennison (Open Data Institute) ● Johnny Stewart (GP, RCGP) ● Stephen Evans (OpenSAFELY researcher; Professor of Pharmacoepidemiology, LSHTM) ● Sam Smith (MedConfidential) ● Alex Freeman (Executive Director, Winton Centre for Risk & Evidence Communication, University of Cambridge) ● Sean Kirwan (OpenSAFELY NHSX IG; Senior Data Sharing and Privacy Manager, NHSX) [SK] ● Tariq Khockhar, Head of Data for Science and Health at Wellcome Trust ● Emily Herrett - LSHTM (researcher observer)
Apologies	<ul style="list-style-type: none"> ● Jess Morley (OpenSAFELY; Policy Lead, DataLab) [JM] ● Rony Arafin (ApHA) ● Hilary Winstanly (OpenSAFELY Admin Support) ● Wendy Harrison (OpenSAFELY NHSE IG; Senior Lead – Data Governance / Deputy Head of Corporate Information Governance, NHSE) ● Simon Madden (OpenSAFELY NHSE/X Sponsor; Director of Policy & Strategy, NHSX) ● Chris Bates (OpenSAFELY-TPP; Director of Research and Analytics, TPP) ● Shaun O’Hanlon (OpenSAFELY-EMIS; CMO EMIS)

Agenda

Documents circulated in advance:

- Meeting notes 13/05/21 OpenSAFELY Oversight Board Agenda (for approval)
- OpenSAFELY development roadmap (for information)
- Dashboard of Approved Projects (for information)

Item	10:00 - 12:00	Topic
1	10:00 - 10:10	Introduction from the Nigel Shadbolt (chair) <ul style="list-style-type: none"> ● Request for AOB ● Review actions
2	10:10 - 10:15	TOR amendments [Amir Mehrkar]
3	10:15 - 10:45	New developments and progress against milestones (Ben Goldacre) <ul style="list-style-type: none"> ● Resource ● Staff ● Datasets ● Research outputs ● Tech (Sebastian Bacon) ● Onboarding of external researchers (Amir Mehrkar)
4	10:45 - 10:50	Patient and Public Involvement and Engagement (Jessica Morley) - <i>Apologies given as JM away - content to be discussed at the January 2022 Board.</i> <i>Board provided with link to review</i> <i>https://www.thedatalab.org/blog/190/opensafely-public-opinion/</i>
5	10:50 - 11:00	BREAK
6	11:15 - 11:50	Open Discussion (Nigel Shadbolt)
7	14:50 - 15:00	AOB (ALL) <i>NONE DISCUSSED</i>
8	Actions	

Item 1: Introductory discussion

Decisions:

- Meeting notes ratified

Discussion points:

- The board discussed the need for representation of patient representatives on the board

Actions:

- Add a PPIE deepdive to the agenda for the next board meeting, including a discussion of patient representation on the board

Item 2: Terms of Reference

Decisions:

- ToR revised:
 - Becky Lumbard, DataLab project manager, included as a member of the Oversight Board secretariat
 - Timing of publication of board meeting notes added: “minutes will be published on the OpenSAFELY website within two weeks of being ratified at the subsequent board.”

Discussion points:

- None

Actions:

- None

Item 3: New developments and progress against milestones

Decisions:

- None

Discussion points:

- Resource:
 - In response to a question regarding funding, it was discussed that OpenSAFELY currently has funding from UKRI (via MRC and the National Core Studies programme) and NIHR for research, and from the Wellcome Trust for platform development. The team will continue to apply for grant funding throughout 2022 to ensure sustainability of the platform.
- Staff:
 - The board heard that the OpenSAFELY team is continuing to grow, with new developers, a new project manager, and new researchers all joining the team over the past quarter. In addition, OpenSAFELY is now beginning to second staff from other NHS organisations, such as NICE, as part of its commitment to community and capacity building. Further recruitment of both kinds is expected in the new year.
- Research:
 - In response to a question regarding PPIE, it was explained that OpenSAFELY is responsible for conducting PPIE with regards to platform development, and a detailed discussion is planned for the next board meeting, it is not currently the responsibility of OpenSAFELY to oversee the PPIE activities conducted by individual research teams using OpenSAFELY. Applicants are subject to ethical approval, where appropriate. This will be kept under regular review and, if proportionate, the OpenSAFELY team will consider asking to see evidence of PPIE in the application form.

- Datasets:
 - In relation to the addition of new datasets to the platform, it was discussed that new datasets are added when a specific COVID-19 research question makes it necessary. There is now a data ingest form that can be used by any OpenSAFELY researcher to request a new dataset, subject to appropriate approvals and prioritisation processes. All datasets currently available via OpenSAFELY are listed in the public documentation.
- Tech:
 - The board discussed the OpenSAFELY roadmap, and reviewed the lay explanation of how OpenSAFELY works on the website.
- Onboarding external users:
 - The board reviewed the newly available public dashboard listing all research projects that have been approved to run using the OpenSAFELY platform. It was noted that this will be regularly updated. It was also discussed that there are plans to streamline the application process, and make it accessible via a web form.

Actions:

- Update on the new onboarding process to be provided at the next available board date.

Item 6: Open Discussion

Decisions:

- None

Discussion points:

- PPIE:
 - The board recognised the fact that it is currently difficult for lay members of the public to review the outputs of OpenSAFELY and, in particular, to discern the specific benefits to patients of specific research projects. It was acknowledged that publicly demonstrating benefit is crucial to maintaining the social license for accessing patient data for the purpose of research. It was noted that, although some progress in this regard has been made much more can be done and that this will be a priority in the New Year.
- Promotion:
 - It was discussed that whilst single research outputs from OpenSAFELY have received significant press coverage over the past 18months, and there has been high impact media coverage on the platform itself (eg [The Economist](#), others), it would be useful to more energetically promote the benefits of the platform approach itself for the NHS, for patients, and for the COVID-19 response. It was suggested that a roundup be written and made public and that the press page be made more prominent on the website. These suggestions were noted and will be followed-up by the OpenSAFELY team, with a deep dive on PPIE at the next meeting.
- Service Wrapper:

- The board discussed the fact that whilst OpenSAFELY’s primary focus is ‘technical,’ the team are also currently dedicating significant time and resource to ‘service wrapper’ activities, including onboarding new users, and output checking. It was noted that, as the number of users of the platform increases, more support in these areas might be needed. The board noted that the OpenSAFELY team regularly reviews their options in this regard and are open to all suggestions. This is a key strategic choice: whether to focus on more users, or developing new features. This choice is made more difficult by the fact that there is plenty of funding for single analyses by our own researchers, but it has (to everyone’s surprise and disappointment) proved extremely difficult to get funding to support the platform as a service for all to use (which is our key objective).

Actions:

- A discussion on making the research outputs, and benefits of the platform, publicly accessible to be included in the PPIE deep dive at the next board meeting.

Actions Log

Item	Action	Owner	Status Notes
6	Upload May board meeting notes to OpenSAFELY website	AM	Complete Link: https://www.opensafely.org/governance/
7	AM to discuss relationship of OpenSAFELY wording in TOR with NHS England / Wendy Harrison	AM	Complete TOR amended from: ‘The OpenSAFELY team working <u>on behalf of NHS England is collaborating closely with Data Controllers</u> on establishing the best methods for evaluating potential users’ skills and projects...’ To: ‘The OpenSAFELY team is collaborating closely with Data Controllers (<u>principally NHS England</u>) on establishing...’

8	Create public dashboard of all approved external researcher pilot applications	AM	Complete https://www.opensafely.org/approved-projects/
9	Email board to arrange a sub-committee meeting of members interested in proposing KPIs.	AM	Open
10	Draft a letter from Nigel and the Board to key stakeholders to gain support?	BG	Open
11	Approved project page to include dashboard of internal DataLab/LSHTM projects for January 2022 Board	AM	In progress
12	Work with researchers to prepare a lay summary of project outcomes/benefits.	AM	In progress
13	Provide the board with a PPIE deepdive at the next board meeting	JM	In progress
14	Provide the board with an update of the online onboarding process at the next board meeting	AM	In progress

END